March 7, 1986

Dear Gail,

Your letter of February 17, 1986 was very well received. I had been looking forward to hearing from you for some time. Your words madethe wait worthwhile. Believe me, I know how life's daily demands can fill up each day and leave you with little time or energy for written communication by the end of the day. There never seems to be enough time in the day for me, no matter what time I get up or how hard I run. And I'm not responsible to a spouse and daughter.

I really appreciate your looking out for Mom, especially during those tough winter months when she can't get out much. I do the best that I can from here with letters, phone calls, flowers, gifts, and monthly checks. But there is no substitute for a warm body right there to give hugs, kisses and that reassurance that she is not forgotten. Loneliness and depression can be harder on her health than anything else. I am very pleased that you got her to another physician. Every time I heard about the former one it seemed worse.

My troubles of late December and most of January seem to be simmering down. To recap , I entered the hospital on December 31st with low back strain (probably seconday to 3 days of coughing due to bronchitis) and was released after 4 days in pelvic traction. I took a week off from work after release from the hospital and was feeling much better, though not perfect by the time I returned to work. By the end of a 12-hour shift I was usually beginning to get very uncomfortable. But with careful body mechanics, avoidance of heavy lifting, heating pad, and pain pills the pain has gradually subsided. An attempt to gradually return to regular exercise seemed to exacerbate the situation, so I've put that on hold for the time being.

I had been seeing a chiropractor 3 times a week during November and December for right neck and shoulder muscle spasms. The neck seemed to be getting better but the improvement was not dramatic and I still had some very painful days. Further, the treks to the chiropractor's office were extraordinarily inconvenient and expensive ($45 a visit). I was already seriously considering discontinuation of the "adjustments" when the low back problem developed out of the blue. This seemed very strange to me since I had never had a back injury and never had more than very minor , transitory back discomfort many years ago. For a new problem to develop while I was undergoing adjustments to my spine seemed justification for seeking a new mode of treatment. It might even be evidence to suspect that the chiropractic treatments had caused the problem. In any event, I will not be returning to the chiropractor. And, for what it's worth, after 2 months of no chiropractic treatments, my neck is at least as well off as it was during treatment.

I don't think that my neck and back problems are related to any underlying health problems. However, I do have some very serious concerns regarding AIDS and AIDS Related Complex (ARC). In order for you to understand where I am at the moment with these concerns, it's probably better to start at the beginning and look at a chronological sequence of events that have taken me through quite a range of emotions from icy fear, to depression, to anger and dispair.

Early in 1984 I noted some changes in my tongue that involved a change in color and texture along the midline and toward the back. The size of the lesion varied greatly from time to time and sometimes it became mildly sore and/or developed small transitory white spots. Visits to ENT specialist and an oral pathologist, various lab tests produced no diagnosis. Yogurt mouth washes and restriction of some foods (nuts, chocolate, vinegar, citrus, raw veggies) made no significant

change and were discontinued after about six weeks. The condition seemed to totally resolve on its own after six to eight months and was forgotten.

Along about Thanksgiving time 1984 I came down with a sudden overwhelming infection in my sinuses, throat, and chest that was scary by virtue of its suddenness of onset and severity of symptoms. It involved fever, night sweats and fatigue, horrendous cough with heavy sputum production. Like any gay man, I had previously considered my high-risk status for AIDS, but this was the first time that I had felt that "this is it!" I thought sure that I was rapidly sliding into pneumocystis carinii pneumonia (PCP) that attacks so many people with AIDS. I expressed these concerns with my internist (Dr. Mende). He was very reassuring and told me that I simply had what was "going around" and that he was sure that it would respond rapidly to antibiotics. Well, it did. But I couldn't seem to get totally well. I'd improve greatly in my chest but retain a low-grade sinus infection. And for four months I went through one antibiotic after another, always improving while on the antibiotic, but two weeks after completion of the medicine the symptoms would return. I continued to work and go to school during this time and do my best to hide my symptoms. So, although I was physically uncomfortable I simply was not incapacitated. The mental anguish over the possibility of being immuno-suppressed was the worst part.

In early March of '85 I learned through the local gay press of a drug called isoprinosine that was classed as an "immune system booster" and had reportedly been very effective in boosting immune system response in people with AIDS-related symptoms. Though not approved for use in the U.S., the drug was readily available in Mexico without a prescription and could be brought across the border in personal-use quantities. I went the next day to Tijuana and got a month's supply for about $25.

At this time, I was on my sixth antibiotic and was getting worse. After two weeks on the isoprinosine I had marked improvement. The chest congestion and cough disappeared, sputum production was greatly decreased, and I felt much better. It was nice to feel better, but the fact that I had apparently responded to an immune system booster seemed a rather ominous sign. The next obvious thought was "How long will the improvement last? How long should I be on the isoprinosine? Are there any dangers to long-term isoprinosine therapy? My doctors knew nothing of isoprinosine and could not advise me. The only literature I could find on my own said only that one month's isoprinosine therapy had been shown to boost the immune system for up to six months. So I did not continue the isoprinosine beyond one month. I decided to wait and see what would happen and hoped that the whole thing was one big coincidence. The chonic sinusitis lingered and I learned to live with it.

In June when I completed my volunteer training at the San Diego AIDS Project and became an "official volunteer" we volunteers were urged to get an immune system check-up just to learn the status of our own health prior to coming in contact with people with AIDS. The Project even arranged a group discount check-up for all volunteers. The check-up included a CBC and three skin tests for immune response. The CBC indicated the presence of an acute viral infection. None of the skin tests reacted--indicating an impaired immune response. The HTLV-3 antibody test which had only just become available was positive--indicating that I had been exposed to HTLV-3 (the AIDS virus). A follow-up blood test for CMV (Cytomegalo virus--a virus often found in combination with HTLV-3 in people with AIDS) was positive. Further, I have had a recurring herpes condition on my sacrum since 1978. So there was no need to test for HSV (herpes simplex virus) which also has a high correlation with HTLV-3. All lousy news.

After consulting with the doctor, I went on a month of herb, megavitamin, and isoprinosine and underwent more skin testing and another CBC. One of the skin

tests showed improved immune response. But the CBC showed a mild anemia and I gradually began to notice mild fatigue. With the exception of the continuing sinusitis, I felt pretty good and had an active summer.

In September, through a research program at UCSD Medical Center, I had a series of other tests done. The good news is that they were unable, with two separate blood draws, to culture the HTLV-3 from my blood. The bad news was that my T-cell ratio (which compares the number of T-4 cells to the number of T-8 cells) was 0.65. It should be 2/1 (or 2).

I continued to be well until 2 days after Christmas when I developed that episode of bronchitis that you already know about followed by the low back strain. While lying on my back for 4 days in pelvic traction, I had an opportunity to do some serious thinking--thinking that I had beed consciously avoiding for some time. I could no longer deny that I have AIDS Related Complex. Up to that point I had fit all the laboratory criteria for ARC but none of the clinical criteria--with the posssible exception of the fatigue (which may have been due to psychological depression). See attached information sheet on ARC. At that point I felt that ignoring a diagnosis of ARC because my fevers, lymphadenopathy, diarrhea, and night sweats, had not persisted for 3 months or more, but rather had been intermittent, was a head-in-the-sands approach.

I had a meeting with Dr. Mende, laid my cards on the table, presented him with the latest information on a combination drug therapy using Isoprinosine and Ribavirin (an antiviral that has shown some effectiveness against the AIDS viris) and asked him if he would monitor me while I was on these drugs. Though he carefully avoided using the word "ARC", he did say that he thought that what I said made a great deal of sense and that I was taking a level-headed approach to the situation. By-the-way, the antibiotic that Dr. Mende had me on for the bronchitis had very little beneficial effect. The symptoms resolved only after two weeks on the isoprinosine/ribavirin therapy. After I started figuring all this out, I realized that the onset of this most recent episode of bronchitis had occurred just six months after I had discontinued the isoprinosine last summer. (Remember what I mentioned earlier about the effects of isoprinosine lasting about 6 months?)

Though ribavirin has been in regular use as a broad-spectrum anti-viral in sixty-some countries--can you guess--the U.S. is not one of them. So that means thatI have to go to Mexico for that one too. The two drugs together cost $150 to $170 per month, depending on the exchange rate of the peso. My insurance company will not pay for either of the drugs because they are not prescription drugs, nor are they tax deductible for the same reason. One more reason to be outraged at the FDA and the U.S. government for the way they have been handling people with AIDS and people with ARC.

The past six weeks I have had an unrelenting outbreak of herpes in my mouth--throat, uvula, hard and soft palate, tongue, gums--for which I am taking acyclovir, an antiviril specific for herpes. That is available in the U.S. for $48 a month (employee discount price). So you can see that without even counting the cost of pain pills for the lymphadenopathy or the megavitamins, I'm shelling out more that $200 a month just for drugs.

The whole thing about herpes in connection with AIDS and ARC is sort of mystifying. For a long time it was believed that herpes simplex 1 caused cold sores and fever blisters, and herpes simplex 2 caused genital herpes and infections of the sacral and buttocks areas (any area below the waist). Now nobody seems to know whether the overwhelming herpes outbreaks of the mouth commonly experienced in AIDS and ARC are simplex 1 or 2. It may seem like a moot point until you start wondering how you contacted them in the first place. I never had a cold sore in

my life until about a year and a half ago when these painful lesions showed up in my throat. The incubation period is thought to be six to ten days. At the time of the first lesions in my throat, it had been 4 to 5 weeks since any sexual contact or any other contact that might have transmitted the viris. Prior to that I had had sacral herpes that presented as a dime-size lesion every 3 to 4 months, scabbed over after 5 or 6 days and then disappeared. So when they showed up in my mouth without reasonable explanation, I began to wonder if they had traveled through my blood to their new site or if I had cross infected myself with my hands--you know, scratch your ass, pick your nose.

So what does all this mean? My current symptoms are sinusitis, fatigue, sore lymph nodes, and oral herpes. None of these things are life threatening, though when they all gang up at once they can be incapacitating or at least reduce ones activity. The question is which direction, if any, are things headed. There's no way to know for sure. And that's why it's like sitting on a time bomb. Some studies have show that approximately 20% of ARC patients go on to develop full-blown AIDS within 15 months of meeting the ARC criteria. What happens after 15 months? I've found no answer to this question. It will just take more time and more research.

An AIDS diagnosis cannot be made (no matter how many opportunistic infections the patient may have) unless the patient develops Kaposi's Sarcoma (KS) or Pneumocystis Carinii Pneumonia (PCP). That is by definition set down by the Centers for Disease Control in Atlanta. A small percentage of ARC patients have died with ARC without ever having met this strict criteria for anAIDS diagnosis.

In spite of my health decline over the past year, I am encouraged for a couple of reasons. (1) We have a great deal more information now than we had just a year ago, especially about the drugs that I am on. (2)Being able to take some positive action in my behalf instead of simply waiting for the next crisis is wonderfully therapeutic. To be sure, I have some down days, and some days I don't even want to get out of bed. But overall, I think I am maintaining quite well. I have loving, supportive friends who help sustain me in times of crisis and that makes all the difference in the world.

Further, my life's experiences have brought me through some tough times, including face-to-face looks at death (Vietnam, near drowning, cancer). I have learned and grown and developed my beliefs and philosophies about the meaning of life and death...death as another stage of life. I have run the scenario of my own passing through my mind a thousand times in the past two years. The fear that once was there is at least for the present gone. I hope for an improvement in my health and a cure for AIDS asap. But I will handle whatever comes my way.

It has been very difficult to write this letter because, though you said that you wanted to be kept informed, I have a feeling that you are rather bummed out at this point. And I don't want to do that to you. But the alternative is to keep you in the dark, and that doesn't seem right. Please forgive me for waiting this long to speak up. But I had to know whether you were receptive. Your last letter opened some doors that seemed to have been closed for some time, and I thank you for that. You touched all the right places. I hope that you will not share any of this health information with Mom. I think it would worry her unnecessarily at this point.

Gail, I have quite a few other things that I'd like to talk to you about, but it is 3 AM and this letter has been in progress for a week. Feel free to call me if you have questions or comments.

I love you and I need your love.

Bob